

## Health and Social Care Committee

### One day inquiry on wheelchair services in Wales

#### WC 5 Evidence from Contact a Family

Contact a Family Wales supports families with disabled children and those with other health conditions. We respond to individual enquiries from parents and professionals across Wales on all aspects of caring for a disabled child, run parent workshops and family events as well as campaigning to improve the lives of disabled children and young people in Wales.

We gave evidence to the previous inquiry into wheelchair services and welcome the opportunity to revisit the work of the previous Committee and investigate progress made on the 23 recommendations.

#### **Key issues:**

Recommendations 1, 2 and 3

We are unaware of any progress on the full national service specification. There is little clarity on strategic planning for the service and on the status and availability of the outcomes from Phase Two of the government's review of wheelchair services, which is not available on the WG, WHSCC or ALAS websites.

Recommendation 4

There still do not appear to be clear and transparent responsibilities and lines of accountability for service delivery from Welsh Government level, through WHSCC to the two ALAS centres. The need for strong leadership remains to oversee and push through the changes recommended by the previous Committee and Phase Two of the wheelchair services review.

Recommendations 5 and 6

We are not aware of any new performance indicators for the service. If they have been drawn up they are not easily available or accessible on either the WHSCC or ALAS websites.

Recommendation 7

We believe that the Children's NSF waiting time targets for assessment and delivery have not been fully met, despite the investment of £2.2million additional funding. We have however received some positive reports from parents that they have noticed an improvement in waiting times for assessment and delivery in the past twelve months, others have reported no change.

*"I am OT working in social care. Assessments have been carried out quite swiftly, within several weeks. This is much improved. Wheelchairs still take several months to be delivered but this too has improved"*

*"This is our first wheelchair and we waited over 3 months (for an assessment)"*

*"It took at least 12 months to get an assessment. It is a little longer than the last time my son was assessed"*

*"The assessment took 3 months to happen from a request from the school. About the same time as the last one"*

*"Our daughter was reviewed in November 2010, and a poor decision was taken on a manual wheelchair, so that when she got her new larger wheelchair in about July 2011 (8 months or so later) it was not suitable, so following another review we finally got the one she has now in January 2012. This came in within the timescales set - as I think it was ordered towards the end of the summer. The new chair is fantastic and she's improved dramatically in her mobility in it. She should have had it first time round (Quickie Youngster as opposed to the Invacare ones she had previously)"*

*"My son had his last manual chair 4 yrs ago aged 9, he is now 13 and almost falling out of the chair, however I have just received a letter from ALAS wheelchair service telling me they are now seeing people that were referred in October 2011 and that my son is now on the waiting list until further notice.*

*T Delivery has not improved. Once the waiting time was so long from referral to delivery, that my son actually was too big for the new chair that was delivered, so they lent him an adult chair for 6 months until they could provide him one with the right support"*

*"The new wheelchair they were going to give my daughter was brought 18 months before she was able to finally use it as they needed to adjust it. It was finally delivered to us in October 2011, but it was not until January 2012 that they finally adjusted it & got the fit right for my daughter finally to be able*

*to use it. During the time we had it we had to keep phoning them & telling them it was not right. Meanwhile we insisted we keep her old chair until the seating on the new one was right. By October 2011 the old chair was bruising my daughters hips as it was too small, but even with the bruising it was a better fit than the new one which was unusable until Jan 2012"*

*"We waited 9 months (for delivery). This about the same time as the last one"*

We would be concerned that any progress made on waiting times for children and young people must reach those with the most complex needs. In our previous experience with Disabled Facilities Grants positive progress was achieved much more readily with the small to medium size adaptations whilst the more complex cases remained much more difficult to address. We would not want this to happen with any initiatives to improve waiting times for assessment and delivery of wheelchair services.

## Recommendation 8 and 9

Some families have reported that communication with the various aspects of the wheelchair service has improved on an individual basis over the past twelve months, whilst others still experience difficulties.

*"Yes, (communication has) improved since 4 years ago"*

*"Communication is always pleasant and effective (Social Care OT)"*

*"If we ever have a problem the emergency/out of hours response is always fairly quick (they usually call back if you leave a message) however if a part falls off or the tyres need changing it is almost always several weeks or more than a month before it gets fixed"*

*" This has not improved as much as I'd hoped. Ideally we would be given written advice explaining what the expected timescales were, and contacted in the event of any delays - but when there was a significant delay to the delivery of the chair in July 2011 I had to keep phoning to find out what was happening - as previously. In fact, I don't think I can point to any real improvement in this area"*

*" Because my son has an Occupational Therapist, all communication with the wheelchair service is done through her. I only hear from the wheelchair service when a wheelchair is ready or not"*

*" With all the difficulties we have had would not like to say"*

*"No communication feedback from the service. When we called for an update on delivery we were told for 6 months that they are waiting for parts from France!!"*

*"No communication at all - my son has had a wheelchair - provided some 18 years ago, reviewed once and had new chair about ten years ago and no communication since - needs a maintenance service at the very least !!!!!"*

Both on an individual and strategic level communication could be improved, with much better use of the WHSCC and ALAS websites to provide information on the wheelchair services, referrals, assessment process, equipment, review and maintenance. As well as publicising the full national service specification and new performance indicators for the service when they are available.

## Recommendations 11, 12, 13, 14, 15, 17

We are unaware of any work undertaken to calculate the long term resource needs of the service in particular to reduce waiting times, promote joint working, streamline referrals, provide sufficient therapists, joint funding arrangements or use of pooled budgets.

#### Recommendation 16, 20 and 22

We have received reports from parents that there have been improvements to maintenance, repair and review over the past twelve months, although others still report delays.

*“Generally this is quite good too. Chairs from rehab engineering are usually looked at within the week and sometimes sooner (Social Care OT)*

*“ No maintenance, unless something goes wrong and are on a call out to fix it, they usually give the chair a QUICK once over”*

*“This has been a bit better. Previously I remember calling an unanswered telephone over and over again and eventually giving up. It is easy now to get someone out to carry out some maintenance, but they often do not have a part, or there is some other reason why the problem can't be sorted. It's normally better to take the chair into ALAC and get the technicians there to look at it, in my experience”*

*“ After waiting to see the OT for 12 months, she agreed the wheelchair was too small, none of her tools fitted in order to extend different parts of the chair and we haven't seen her since”*

*“ I think they are trying. When I asked the occupational therapist for help to chase it up, she gave the advice 'Make a bloody nuisance of yourself as that seems to work!’”*

*“None!!!! And not for the past 10 years or so since delivery.”*

#### Recommendation 21

We are unaware of any communication with users in regards to the renewing of tenders but have received positive feedback since the tender for maintenance was removed from SERCO.

#### Recommendation 23

We have received positive feedback from parents in regards to training in the past twelve months, although this has been provided by Whizz-kidz (and previously by Contact a Family Wales). We do not believe that this was funded from the additional £2.2million allocated to wheelchair services this financial year despite a budget of £200,000 being pinpointed for wheelchair training.

*“(We have had training) through Whizz-kidz”*

*“ Advice and guidance is always provided and children informed/ signposted to wheelchair skills courses (Social Services OT)”*

*“ We have had no wheelchair training at all. When my son first started using a*

*wheelchair it was his OT that practised with him at school”*

*“This has been really good over the past year. (My daughter)went on a Whizz-kidz*

*course that was brilliant, and well-attended by the ALAC team - who spent a fair bit of their time tweaking wheelchairs, assessing children and doing all kinds of things that you'd imagine would be better done back at base! We've been offered another course since then. The courses are excellent and a good opportunity especially for children in mainstream schools to meet other wheelchair-users”*

*“ We have only ever been offered wheelchair training by Whizz-kidz”*

*“Absolutely none, in fact the training we did used to get once a year has stopped as it was organised by Contact-a-family & the funding has been stopped”*

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